



# **Invest in ME Research**

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## **Myalgic Encephalomyelitis (ME)**

12 September 2017

Dear Valvira,

Invest in ME Research is a UK charity that aims to educate and campaign for research and funding for the neurological illness myalgic encephalomyelitis/chronic fatigue syndrome (ME or ME/CFS).

Invest in ME Research are founder members and current chair of the European ME Alliance, a group of 13 European national patient organisations campaigning for ME/CFS awareness and research in Europe, and including Finland.

We saw your recent announcement regarding Dr Olli Polo's suspension and lack of care pathway for Finnish ME (CFS) patients, and that you mention that patients should be offered Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET). [1]

We would like to suggest that this recent announcement advising the use of CBT and GET for ME is the completely wrong course of action to take.

Neither of these therapies are effective for ME and one can look to the UK to see this.

**The UK National Health Service (NHS) is currently wasting a huge amount of funds in giving these failed therapies to ME patients which are either useless, or deleterious to the health of ME patients.**

More importantly, these therapies are rejected by patients and, at a time where health services such as the NHS needs all the funding it can get, there is no sense in wasting resources or funds like this by any health service.

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We would also like to point out that there is great international concern regarding the evidence base for CBT and GET for ME (CFS). So much so that the US CDC have removed these recommendations from their website and the US Agency for Healthcare Research and Quality (AHRQ) has downgraded the evidence for these therapies due to the criteria being used for CBT and GET research [2].

Also the US Institute of Medicine (IOM) report that was published in 2015 [3] reviewed all the ME (CFS) research literature and renamed ME (CFS) as SEID (Systemic Exertion Intolerance Disease) **reflecting the intolerance of any form of exertion (physical or mental) by people with ME.**

We need to do things differently if people with ME are to be served safely and effectively and it would be advisable for the Finnish healthcare system to learn from the terrible mistakes and policies that have been forced on patients with ME in UK.

Invest in ME Research aims to educate and campaign for research and funding of the neurological illness myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Each year we organise a CPD accredited **International ME Conference** and **Research Colloquium** in London.

Next year will be our 13<sup>th</sup> Conference and 8<sup>th</sup> Research Colloquium with researchers and delegates attending from almost twenty countries.

We would like to invite Valvira to send a representative to learn more about international progress in ME (CFS) biomedical research to help Finnish ME (CFS) patients. These events take place in London as follows – on 30-31 May 2018 (researchers Colloquium) and 1 June 2018 (public Conference).

We have NIH and CDC attending these events, as well as the Norwegian Research Council. We also have attendees from all the major international research institutes involved in ME (CFS) research.

By attending you could possibly avoid expensive and damaging mistakes being performed as well as be better equipped to understand the research into ME that is underway.

The charity continues its efforts in establishing a UK Centre of Excellence for ME in the UK and is currently funding and facilitating biomedical research into ME/CFS at UCL in London and University of East Anglia/Quadram Institute Biosciences in Norwich – with links to other universities in Europe and USA.

We have also facilitated the establishment of a European ME Research Group (EMERG).

You may find out more of this, and other research at our events.

Thank you in advance for your consideration of our request,

Yours Sincerely,

Invest in ME Research

## **References:**

- 1/ [http://www.iltalehti.fi/kotimaa/201709042200370930\\_u0.shtml](http://www.iltalehti.fi/kotimaa/201709042200370930_u0.shtml)  
<http://www.valvira.fi/-/kroonisen-vasymysoireyhtymän-hoidossa-tarvitaan-toimivaa-hoitopolkua>
- [2] CDC <https://www.cdc.gov/me-cfs/index.html>  
USA AHRQ <https://effectivehealthcare.ahrq.gov/topics/chronic-fatigue/research/>
- [3] Institute of Medicine (IOM) entitled "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness" -  
<https://www.ncbi.nlm.nih.gov/pubmed/25695122>  
IOM <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>
- [4] <http://www.investinme.eu>